

To: Texas Legislature, Governor Abbott, Texas HHSC

c/o: Ms. Courtney DeBower (courtney.debower_hc@house.texas.gov), cc: Governor Abbott
(governor@state.tx.us)

From: Dr. Theresa M. Edgington, PhD

I am writing to advocate for those in profound need of intervention, our elderly. Many of them are being neglected when they are most in need. During this pandemic, under the guise of 'safety', they are dying, injured, alone, and fearful for months on end, knowing that relief is just an essential caregiver away.

My 99 year old mother has never been diagnosed with dementia; however, I see the stress of this lockdown not only increasing her fear, but negatively impacting her cognitive ability. She is afraid to go to sleep due to the isolation from her essential caregiver, me. Mom wakes up every hour or two and seldom gets a restful sleep. I have a camera in the living area, so I can see her sleeping in her chair, but she cannot see me. She never slept in her chair before, always in her bed, but has become fearful and is sleeping in a chair not made for sleeping. She simply has no one to work with her on a cognitive or occupational health perspective. Mom has been injured because the environment was not observed that it needed correcting for an elderly woman, with mobility issues and very, very poor eyesight. There are missing items: a missing hearing aid, missing jewelry, missing clothing, missing medical supplies. I doubt anyone took them, but she cannot see very well and it also hurts her back quite a bit to look through the dresser drawers. The staff do not know how to look for things, leaving them organized so she can find them, so she is fearful to ask them. In fact, the staff really does not want to repeatedly look for things. She is so lonely, so stressed, so fearful of having this existence be the last she has before she dies. Mom relies heavily on me and it is obvious how well she does when I am with her. I am her lifeline and you have taken that away from her.

I am advocating for essential caregiver status being permanently authorized for those in long-term care (LTC) facilities: assisted living, nursing homes, group homes, skilled nursing, or any community where elderly who may not be able to advocate for themselves may be residing. One essential caregiver should never be denied the type of contact that is available to staff. Essential caregivers can be screened and go through all the precautions expected of any staff member. Their involvement improves the general health at long-term care facilities rather than decreases it.

My own direct experience is with assisted living facilities, so the nuances of the other communities may be best advocated by others. However, there will be some commonalities and overlap. My advocacy focuses on three perspectives: Emotional, Spiritual, and Analytical.

Emotional:

To gain a deep account of the Emotional cost: I urge you to request to join Texas Caregivers for Compromise, a Facebook group. Read as many accounts as you can. I would fill up the entire space allowed to me for this entreaty and still fall short of the traumatic experience being inflicted on LTC residents, including deaths, solely from the far-too extreme lockdown in LTC facilities. If you do not see that the pain being inflicted, by not offering an Essential Caregiver authorization, is severe, extensive, and yes, unnecessary, I would ask you to consider strongly where your priorities lie. I am a retired professor and my research was heavily, and quantitatively, focused on problem-solving, failure analysis, and anomaly resolution processes. My underlying theory showed that groups generally share values, but problems arise when the priorities are lopsided. Think of it as a recipe; one does not make a sandwich of mustard, but it is often useful to have the ingredient in less-

than-dominant quantity. Some values we hold should just be considered more as condiments than as the main event. And following along this analogy, the best recipes have a variety of elements, not just one ingredient. A lockdown is a condiment and not a recipe for the safety of our LTC residents.

I estimate that the lockdown, not the pandemic, has taken 1-2 years of life from my mother, at best.

Spiritual:

Many of you consider yourselves to be good Christians, and others may at least share the same God, the Father, or at least the essential values in living that religion is supposed to encourage. Scripture is quite clear on taking care of the vulnerable, and here are some passages worthy of highlighting:

Exodus 22:22-24: You shall not mistreat any widow or fatherless child. If you do mistreat them, and they cry out to me, I will surely hear their cry, and my wrath will burn...

James 1:27: Religion that is pure and undefiled before God, the Father, is this: to visit orphans and widows in their affliction, and to keep oneself unstained from the world.

Proverbs 21:13: Whoever closes his ear to the cry of the poor will himself call out and not be answered.

Psalms 68:5: Father of the fatherless and protector of widows is God in his holy habitation.

Deuteronomy 27:19: Cursed be anyone who perverts the justice due to the sojourner, the fatherless, and the widow.

Mark 12:40: Who devour widows' houses and for a pretense make long prayers. They will receive the greater condemnation.

Matthew 25:40: And the King will answer them, 'Truly, I say to you, as you did it to one of the least of these my brothers, you did it to me.'

Isaiah 1:17: Learn to do good; seek justice, correct oppression; bring justice to the fatherless, plead the widow's cause.

Isaiah 1:23: Your princes are rebels and companions of thieves. Everyone loves a bribe and runs after gifts. They do not bring justice to the fatherless, and the widow's cause does not come to them.

Deuteronomy 10:18: He executes justice for the fatherless and the widow

1 Timothy 5:8: But if anyone does not provide for his relatives, and especially for members of his household, he has denied the faith and is worse than an unbeliever.

1 John 3:17-18: But if anyone has the world's goods and sees his brother in need, yet closes his heart against him, how does God's love abide in him? Little children, let us not love in word or talk but in deed and in truth.

Father, in Heaven, we most humbly ask that you open the eyes of our leaders. Let them realize their scope has been limited. That authorizing even one Essential Caregiver for the LTC resident does more good than harm. That focusing so much on the Economy and so little on Healthcare gravely hurts both.

Analytical:

Within the Analytical context, there are three questions:

- 1) What should it mean when one espouses that they are keeping our loved ones in LTC 'safe'?
- 2) What data is necessary to make that determination?
- 3) At what level should decisions to keep our loved ones 'safe' be made?

1) Safe? To make the blanket statement that someone in LTC is 'safe' requires a broad view. Certainly, if someone is at significant risk of Covid, they are arguably not safe. However, if one is 'safe' from Covid, but at risk of injury, one is not 'safe' in any general context. Similarly, if one is at risk of emotional trauma, isolation, or other environmental threats, one is not safe. If one is not eating well, one is not safe. If one is in constant pain, one is not safe.

Can we even say that the lockdown makes one safe from Covid? In looking at the statewide data, the answer is resoundingly 'no!'not even in long-term care facilities that have been locked down from family, from many healthcare providers, from other service providers for over six months. Residents are contracting Covid and even dying, in spite of the 'safeguard' of preventing family from entering. Obviously, residents are contracting Covid from staff; they have been locked down. From whom do you think is infecting the residents currently? Of course, the workers are bringing it in. Look at the profiles of those who choose to help in these facilities. They are young, generally in their 20s and 30s, the age groups contracting the virus in the greatest numbers. Most are married; their spouses generally work. Most have young children; children who either are socializing and really do not understand the responsibility to physically distance, properly wear PPE, and report promptly when they feel ill. The staff and their spouses are highly unlikely not to be socializing with their own families and friends. Perhaps they took extreme measure for a couple of weeks, but for six months or more? Perhaps they think they are being careful, but numbers show, not careful enough. So, 'NO' from statewide data, the policy of locking out family who are essential caregivers, is not being successful.

Does stress negatively impugn the immune system? Without a doubt. Does pain impugn the immune system? Without a doubt. Does isolation and loneliness impugn the immune system? Without a doubt. Does depression impugn the immune system? Without a doubt. Do any of these conditions discourage one from eating healthy meals or getting sufficient nutrition? Without a doubt. The body does not even process nutrients properly when under these conditions. I ask you to consider how the lack of even one essential caregiver stresses the physical nature of the LTC resident, making them weaker, rather than healthier, should they become exposed to the Covid virus.

2) Do we even have the data needed? Rep. Frank, in a webinar he hosted in August, asked Texas HHSC if they had data on how many LTC residents had died due to problems associated with the lockdown policy? The response from Texas HHSC was that they were not required to do so. This presents two red flags: one, it is a complete admission that they do not have the data necessary to ascertain if residents are actually safe, and two, because they are waiting for someone to require such data, they give evidence that they are not the entity who should be making rules with regard to the lockdown.

3) At what level, should rules relating to lockdowns be made? Just a cursory look at the data on Covid in LTC facilities testifies that situations are different among counties, and even to the county level. In my county, Travis, out of 69 reporting facilities for August 19, Texas HHSC reporting notes that only nine facilities report more than 2 cases of Covid covering both residents and workers. At the start of the outbreak, a tight threshold might have been needed, but since so few facilities seem to have run-away infections, let us set the threshold, hypothetically, at 10. That would allow for one case of Covid every two weeks, assuming data collection was

started at the beginning of lockdown up to August 19. (Of course, if the reported numbers are earlier, the hypothetical threshold would be higher than 10). With that hypothetical threshold, only THREE OUT OF 69 facilities indicate a potential cause for alarm. So, for three facilities, we have enacted and maintained restrictions that are harming the population of assisted living facility (ALF) residents, ALF workers, and ALF residents' families for months. Draconian, perhaps?

Even using the limited data provided by Texas HHSC, it is clear that the lockdown has been too extreme. It may have been appropriate at the start, but certainly no longer. And, it should not take the citizens to be the ones who first understand this. Someone in authority should have had that competency.

I maintain that the appropriate level of analysis for establishing the actual facility rules should be at the facility level. Their management team working with residents and their families have demonstrated that they can manage their facilities. Facility management can work with the residents who make all their decisions themselves to identify a limited number of individuals, ideally family, who can enter the premises. For residents who have medical or durable POAs or guardians, those family should be included in the decision-making process, identifying if they, or other, appropriate family is to enter.

It must be highlighted that medical and durable POAs and guardians have taken on legal responsibilities that have been almost entirely prevented from being executed as required. Legal rights have been removed unnecessarily and without achieving their intended goal, that is, to keep LTC residents safe, not even safe from Covid.

The state level is needed to monitor, guide, and give feedback. They can force a noncomplying facility into a state of emergency, but should not holding a gun to the head of innocent facilities, making a dangerous situation worse than it should be. They should not be able to remove vulnerable residents legal, medical, and emotional support.

The state level should not be applying lockdown rules indiscriminately. A nursing home is not an assisted living home, is not a group home, is not skilled nursing. It is understandable that the state level cannot appreciate the nuances. Their level of analysis, by design, is at a coarse level. The facility level is the highest level that should be expected to contain the Covid virus while keeping an eye to the broader aspects of how to keep each resident safe. Even the concept that the conversation is between HHSC and the facility management is years out of date. Safety in LTC care facilities is a 'wisdom of the crowd' problem; that is, invent processes that allow residents, their family, and their friends to report what is happening and you will have a much more accurate dataset than you have now. I entered the information systems business in 1980. Throughout that time, we have always known that the worst thing to happen in decision making is to have inaccurate data.

The facility should be free to exercise judgement, that even when Covid has hit their facility, that exceptions to their facility-level rules not only can, but should be made. For instance, a resident in another wing of the building tests positive. Obviously, the resident is quarantined and all residents and staff are tested. The facility would know to what extent and by what process others could receive essential caregivers and visitors. At my mother's residence, she and others have back doors directly into their apartments. No one else be put at risk, and facility management know that I am extremely low risk. They also know that I would not put my mother at risk, but would take on the risk of my entering to help my mother. I would just ask that the most logical way of mitigating that risk be used, such as my direct entry into her apartment and not common tables or cubicles used by numerous people for whom I have no idea what their PPE nor protective practices are, and that remove my ability to help my mother make her apartment safe, organized (FOR HER), and comfortable. Do you REALLY think

that over weeks of visiting in the current Phase 1 rules that these overworked staff will be completely disinfecting the tables, chairs, plexiglass, phones, etc. that are utilized over and over? (One other thing that I saw in my research is that executives love to assume the policy is executed as documented....no! It does NOT! Staff, who are already overworked and stressed by dealing with residents so lonely and isolated, are wearing out. By this lockdown, you have set back the quality of care in LTC facilities by years. Do you even know what the turnover rates are for staff at LTC facilities, compared to previous years? I have read articles that nursing homes, especially, are having a terrible time staffing to the levels in which they are needed.

At this point, it must be noted that the state's draconian practices have drained staff, greatly increased turnover, reduced training, and negatively impacted the community atmosphere that will take years to reestablish long after the Covid panic has passed. I would hope my mother will live long enough to see it. She used to think she this facility was the best of the numerous facilities in which she has lived in the 25 years since Dad died, but now she hates it. She begs me to take her out. She understands my own health will not allow it. She is not ready to die, but she wishes she had a chance to live.

I would also like to see data on false positives. I know of two LTC residents who tested positive but stayed asymptomatic until they tested negative. Were they tested incorrectly the first time? Is the virus mutating and not as much of a threat to the elderly? For the most part, the elderly do not enter assisted living facilities unless they have some serious health issue already...the type of health conditions that were supposed to put them at greater risk. Is anyone even collecting data to answer such questions?

Essential Caregivers

The state has recognized LTC residents, LTC workers (and a few others they classify as essential), and visitors. Grossly ignored are family essential caregivers. Even under optimal conditions, none of the LTC facilities are successful without these unappreciated, unpaid, yet unconditionally loving family who make sacrifices few appreciate. Some give up their careers and with that, sometimes substantial, salary. All give up an enormous amount of time. Many are aware that they likely are giving up either years of their life or years of their independent life, as studies show that this type of dedication takes its toll. True love is to will the good of the other, just because that other exists, not for any personal benefit. Essential caregivers work for the benefit of their other. They are happy when their loved ones are happy; they hurt when their loved ones are hurt. They take on some of the suffering of their loved one, if for no other reason than it lessens the pain of their loved ones to know they are there and willing to help as they can.

This pandemic has changed me in many ways. Maybe not as a completely different person, but as one who recognizes that the government approach to healthcare is DEADLY wrong in so many ways. I ask you to consider one, very substantial, way to improve, and that is to recognize that Essential Caregivers are as necessary as any staff at a facility. They are not denied entry. They give up no rights not afforded to paid workers. They are held to the same criteria as ANY worker who can enter the resident's room or apartment.

By following the same protocols as staff, we should see no significant increase in Covid cases in these LTC facilities, but are likely to see many benefits.

Sincerely,

Dr. Theresa M. Edgington, PhD